

SENATE JOINT RESOLUTION 760

By Dickerson

A RESOLUTION relative to the impact of rare diseases.

WHEREAS, a rare, or orphan, disease is defined as a disease that affects fewer than 200,000 people; there are 7,000 known rare diseases affecting approximately thirty million men, women, and children in the United States; and

WHEREAS, the exact cause for many rare diseases remains unknown; however, eighty percent of rare diseases are genetic in origin and can be linked to mutations in a single gene or multiple genes; and

WHEREAS, genetic disease can be passed down from generation to generation, explaining why certain rare diseases run in families; it is also estimated that about one-half of all rare diseases affect children; and

WHEREAS, a person suffering with a rare disease in Tennessee faces a wide range of challenges, including, but not limited to, delays in obtaining a diagnosis; misdiagnosis; a shortage of medical specialists who are familiar with, and can provide treatment for, rare diseases; prohibitive cost of treatment; and the inability to access therapies and medication that are used by doctors to treat rare diseases but have not been approved by the Federal Food and Drug Administration for that specific purpose; and

WHEREAS, in recent years, researchers have made considerable progress in developing diagnostic tools and treatment protocols for, and in discovering ways to prevent, a variety of rare diseases; however, much more remains to be done in the area of rare disease research and the search for and development of new therapeutics; and

WHEREAS, the National Organization for Rare Disorders or NORD has taken the lead in educating medical professionals, government agencies, and the public about rare diseases,

especially the impact of public policy on persons living with rare diseases, but raising awareness about this public health issue remains essential, as does funding research to develop new treatments for rare diseases; now, therefore,

BE IT RESOLVED BY THE SENATE OF THE ONE HUNDRED TENTH GENERAL ASSEMBLY OF THE STATE OF TENNESSEE, THE HOUSE OF REPRESENTATIVES CONCURRING, that this General Assembly recognizes the debilitating effects of rare diseases on thirty million Americans and acknowledges the negative impact of rare diseases on individuals, families, and society.

BE IT FURTHER RESOLVED, that we encourage Tennesseans to learn more about rare diseases and support measures to mitigate their detrimental impact.